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Case conference

Fain would I change that note

The recording and transmission of medical information poses many problems. The patient generally rarely sees his or her notes and possibly gives little thought to how or what is recorded, trusting that the doctor 'knows best' and will be noting, in a professional manner, that which will be useful for the diagnosis.

In the two cases presented, one of the patients sees her notes and is very upset by what she reads, the other requests that certain information be deleted from her case record. The actions of the doctors and patients were discussed in a preliminary conference at a recent postgraduate meeting.

All the names in this Case conference *have been changed.*

Maria

Maria presented herself in tears to her local advice bureau complaining that her doctor was not only not helping her but had also written insulting remarks about her in her notes. She was a 22-year-old who worked for a London fashion firm: her parents were from Cyprus, but she had been born and brought up in England. She had been to her general practitioner a number of times, she stated, during the previous 3 months complaining of headaches, which started when at work and lasted well into the evening. She found herself increasingly unable to do her job which she felt she was well suited to and usually enjoyed. As part of the investigation into these headaches she had been referred to her local hospital for tests, which had included X-rays of her skull and a blood test. The blood test raised the possibility that she was suffering from Thalassaemia Minor, and the pathologist asked her to be sent for further tests. After hearing this news, Maria left her doctor's surgery in panic, as she knew one of her mother's sisters had been suffering from this condition and had died in her teens in unpleasant circumstances in Cyprus. Maria presented herself in the Casualty Department of her local hospital that evening with hyperventilation tetany and was later discharged, remembering little of what had gone on, with an appointment to see a psychiatrist at the hospital three weeks later. She could not remember anyone making any further explanations to her. She then returned to her general practitioner. Her doctor worked upstairs in his practice, and patients about to see him would sit upstairs outside his door with their notes. So anxious was Maria that she took out her notes and read them while waiting, 'in order to get to the bottom of the whole thing'. She was appalled to find that the doctor had written at the heading of the page 'Beware, hysterical and manipulative, determined to be unwell.' She had left the surgery at once to seek advice from the Bureau.

Mr and Mrs Spence

Mrs Spence had considerable trouble in obtaining her present pregnancy. She was the wife of a teacher who was about to leave the locality to take up the post of a headmaster at a boys' public school. Mrs Spence had also been a teacher, but was now not working as she was pregnant. During her previous marriage she had been pregnant and miscarried twice; in fact had never carried a baby to full term. Her previous husband had left her and she felt that her miscarriages had partly contributed to the breakdown of the relationship. Her present marriage was five years old. It had rapidly become clear that they needed infertility investigations and were referred to a private clinic. Here her present husband was found to be infertile and they requested and were accepted for artificial insemination by donor. Because of her previous miscarriages Mrs Spence had a series of hormone injections given by her general practitioner in the early months of her pregnancy. At the last of these consultations, when she was about to leave the practice because of their move to the new district, Mrs Spence asked her doctor to destroy any record of the artificial insemination so that no-one would know about it. She said that she and her husband had discussed this at length, and that they wanted to make a new start, and felt it would be fairer on the child if nothing were known about this. Her general practitioner reluctantly agreed.

CHAIRMAN

This is a fascinating pair of cases which have a common problem. Whose property are the details of a case, and the knowledge and understanding that arise from them? Shall we consider Maria first?

DR GRANGE

There are some glaring mistakes in management that we should touch on, first. It is highly unlikely that Maria is suffering from anything more serious than a tension headache, although she may be on the edge of a depressive illness. These headaches can be very troublesome, both to the patient and to the doctor who has to give satisfactory explanations to an already anxious patient. It is possible that Maria's doctor was driven to apparently unnecessary investigations by factors that we don't know about, but if he thought that it would be a way of straightening out the situation he was sorely mistaken! At no time does Maria remember being given a simple explanation about the relative unimportance of Thalassaemia Trait to her own health, and the difference between this and the disease Thalassaemia Major, which presumably killed her aunt. As a relatively common problem in peoples originating from the Mediterranean coastline, it is hard to imagine she was ignorant of its effects: and her knowledge becomes vital when she contemplates marriage to someone from similar origins. Why was neither the GP nor the Casualty Officer capable of simple and reassuring explanations? We have only Maria's account here, but to her what *she* heard, or did not hear, is all important.

MRS JONES (SOCIAL WORKER)

If a patient is in a state of mind not to accept an explanation, or is clearly too disturbed to remember, surely a recall later when she is calmer is the correct course, not referral to a psychiatrist!

DR SHAW

We don't have evidence on which to judge the actions in Casualty, but we must remember that genetic counselling may be out of place in an Accident and Emergency Department on a busy night! But the central issue is the general practitioner's note. Baldly stated on paper and read by an upset patient it sounds terrible. But, however unkind in content, if he believes it to be a correct assessment of the patient's state of mind, is he to prevent himself writing his assessments?

DR PENROSE

There is a fundamental distinction here. If you write you must know for whom you are writing, and the responsibility must remain with the writer to define the limits of his publication under normal circumstances. A general practitioner's notes are written for himself and his immediate colleagues, and what he writes must help in the management, the total management of the case. It would be ridiculous to be unable to write down details of the case because we were looking over our shoulder at the possibility of litigation. 'Total management' includes an assessment of all sides of the patient and her or his problem that may help to establish a diagnosis and find a solution. Just as the cardiologist must note down his assessment of the blood pressure, so must any doctor dealing in 'whole person' medicine attempt, and attempt to note down, an assessment of social and psychological factors. These will include a person's mood, personality, cultural and social background, and attitudes. This may also be clarified by a description of how the patient makes the doctor or therapist feel, and this may be one of the most useful diagnostic tools, and may help to explain facets of a problem that may defy more conventional analysis.

DR HARPER

The areas you describe are fraught with possibilities of bias, and must surely be seen as a different type of knowledge from the blood pressure. Three different doctors taking the patient's blood pressure in similar circumstances would be expected to get similar readings. The observations you describe are much more subjective, debatable, and therefore much more questionable. Written down without distinction and handed on to another colleague who may not realise the distinction implicit may certainly lead to prejudice. Somehow these subjective areas must be presented differently.

MRS JONES

In Maria's case they were presented differently – they were presented to the patient herself! To her they just assume the status of condemnation and confirm her suspicion that everyone is hiding something from her. It is not difficult to have paranoid fantasies about professional activities anyway, and these may easily be focused onto the notes. There is a 'Catch-22' in so much authoritarian behaviour that can cause trouble even in the caring professions. This is vividly presented in the play *Whose Life is it Anyway?* The paralysed hero wishes to die, is prescribed Valium, and insists that since it is the doctor who is upset by the patient's state and attitudes, and by the doctor's absolute impotence to do anything to change either, that the person who needs the tranquilliser is the doctor not the patient. If a doctor writes his feelings about the patient, he may be giving some useful observations on himself, but in this case we may see him describing a normally anxious lady rendered paranoid by the doctor's inability to communicate adequately.

MR PRENTICE (PSYCHOLOGIST)

This still ignores the question of whether such comments by a professional are in place in the notes, even if justified by every observer at the time. It has been mentioned that this doctor is writing for himself and his colleagues: there is usually less chance of notes being seen in general practice than would notes in hospital, a housing office or school. But the analogy is not unreasonable as these notes, should the patient move, will follow her to her next NHS

doctor, whether she likes it or not, and so are in every sense statements to a wider professional public. She does not have the same benefits as Mrs Spence, who is a middle-class lady with cultural affinities with her doctor, and as such may be more able to impose her wishes on him and prevent information being passed on to the next doctor without her permission, which she sees as a reasonable 'civil right'.

DR HARPER
The most reasonable resolution of the problem would be for the doctor to discuss the statements about a patient with the patient before they are written. The summary in the notes would therefore form a statement which has been reached as a result of agreement. This must be a very satisfactory therapeutic goal in itself. This sort of activity would precede the formation of a contract between patient and therapist that is sometimes used to define therapy in neurotic conditions in psychiatry. It would have prevented this situation, where Maria feels she has a physical illness that everyone is hiding from her, while all her doctors are working along emotional or psychological lines.

DR SHAW
Would this not be enormously time-consuming?

DR HARPER
Put in a formal way as I have done, it would certainly take a lot of time to work out in normal consultations in general practice. But I think something along these lines happens anyway in many general practice interviews, which at the beginning may be about anything from a housing letter to leukaemia. In a few seconds the experienced practitioner – and experienced patient – establish the reasons that they are going to accept for the consultation and what areas they are going to explore. It is when other subsidiary or more important issues are at stake without one party realising it that the interview may become 'dysfunctional', unless there is a reappraisal. Time spent doing this may save time ultimately and not waste it. I am sure Maria's case reveals this.

MR PRENTICE
In Mrs Spence's case, however, I don't think that justice is being done for the patient, who seems in reality to me to be the unborn child. The doctor's actions here seem to go against the trends in modern adoption and children's legislation, which is to provide more information for a child on its origins at a time when the child is mature enough to cope with it. Destruction of this information before the child is born, is not in line with this.

DR GRANGE
Yes, there may be genetic problems which would lead the doctors to wish to know something about the origins, although, of course, genetic counselling does not arise here. There is a difference between this and adoption, however. Here, there is no possibility, as far as I know, of identifying the child's real genetic father, as the information is purely negative. As such, the parents may feel legally that no news may be construed as good news.

MRS JONES
Could this be resolved by some form of independent register?

DR HARPER
I think this is rather too heavy and bureaucratic an approach to a problem which I see as yet again having arisen from too little discussion and preparation by both patient and doctor. 'What are you going to tell your child?' is surely a fair question before anyone embarks on AID and would help all involved to straighten out the approach that the couple have *before* the actual processes (which may be distasteful to them) make them rigid. This discussion makes it clear that there are some general principles to be drawn on the possession of and rights to information.

DR PENROSE
Equally unfortunate results may come about as a result of official policy. Most hospitals destroy notes after a certain time so that the information that this child will want as an adult would be lost anyway in an NHS hospital system. This raises some more direct questions as to 'whose life is it anyway?' I think, if I were approaching a difficult judgement about my medical care, and knew that the doctors were handicapped because the administration had decided to destroy the notes of my previous treatment, I should be very angry. One hopes that this equally may be resolved.

CHAIRMAN
Whose information is it anyway? I suspect this discussion should be enlarged far beyond the strictly medical area. We certainly need a type of civil rights declaration in all areas where private details become potentially public, and yet are denied to the individual himself.